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## SUMMARY

Cancer in children is the second most common cause of death in childhood. Cancer is a class of diseases or disorders characterized by uncontrolled division of cells and the ability of these to spread, either by direct growth into adjacent tissue through invasion, or by implantation into distant sites by metastasis. National Cancer Institute recommended that the HRQL assessment should be a part of clinical trials. Children with cancer are most likely to have disabilities that alter QOL, because cancer has impact on nearly every domain of life and cancer itself and its treatment can cause considerable toxicity and complications. Therefore educational program for mothers is important for optimizing the QOL of the child with cancer and the mothers taken requisite knowledge and practice which the key of effective management.

The aim of this study was to evaluate the effect of educational intervention on maternal management of children with cancer and evaluate the effect of educational intervention on child progress.

### ◆ Research design:

Quasi-experimental design (pre and post intervention) was utilized to fulfill the aim of this study; the methodology followed in carrying out the study is presented under technical, operational, administrative, and statistical designs.

#### I. Technical Design:

Technical design included the setting, subjects as well as tools of data collection.

**♣ Setting:**

This study was conducted in the Specialized Pediatric Hospital oncology department at Benha City.

**♣ Subject:**

A convenience sample of 60 children with cancer and their mothers who are attending the above mentioned setting over 6 months period with the following criteria of inclusion.

**Criteria of inclusion:**

- Mothers having children undergoing chemotherapy
- Gender both male and female
- Age of children from 1 to 15 years
- Children complained from any type of childhood cancer

**♣Tools of data collection:** Data were collected through using the following tools;-

**1- Structured interviewing questionnaire :- ( appendix1)**

It was constructed by the researcher and it consists of two parts:-

**Part I:** Socio demographic data about mothers and children:

- Child (age, gender, diagnosis, and history of disease).
- Mother (age, occupation, and education, source of information).

**Part II:**

-Mother's knowledge about cancer such as concept of cancer, etiology, clinical manifestation, laboratory investigations, complication, treatment, care and follow up).

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## **2- An observation checklist :-( appendix II)**

It was prepared by the researcher to observe mothers' practice related to care of their children it included mother's management related to skin care, oral care, drug administration and bathing).

### **Knowledge scoring system:**

The score of knowledge was divided into two levels, where mothers who were their knowledge scores above 50 %, they considered on the satisfactory level and those who were score below 50 % are on unsatisfactory level.

### **Practice scoring system:**

The score of practice was divided into two levels, where mothers who were their practices scores above 60 %, they considered on the satisfactory level and those who were score below 60% are on unsatisfactory level.

## **3- The pediatric oncology quality of life scale (POQOLS), it will include two parts :-( appendix III)**

**A-** The performance status of children were obtained according to lansky play-performance scale, the scale was adopted from (**Lansky, 1997**) and modified by (**Yaris, 2001**) it consisted of eleven levels and the grades were ranged from 0 to 100%.

**B-**The health utilities index, health status classification system the scale was adopted from ( **Feeny, 1992**) and modified by (**Yaris, 2001**) that developed to assess the health related quality of life, for childhood cancer and focuses on functional capacity rather than performance. It

comprised from six attributes: sensation, cognition, and self-care included 4 levels, and mobility, pain, and emotion included 5 levels.

#### **4- Educational training program handout: (Appendix IV)**

It was prepared by the researcher under supervision after reviewing the related literature which based on mothers' knowledge and practice deficit about childhood cancer. The program was designed to improve the quality of life for children with cancer and enhance the mothers to understand the potential side- effects of the drugs; it was designed in the form of handout.

**Ethical considerations:** The researcher informed all mothers that:

- All mothers' rights are secured.
- Each mothers informed about nature process on expected outcomes of the study.
- All data will be confidential and used only for the research purpose.
- An oral consent was obtained from each mother before starting the data collection

## **II. Operational Design:**

### **1) Preparatory phase:**

A review of the current and past local and international related books, magazines and periodicals to get acquainted with various aspects related to childhood cancer definition, its causes, incidence, its impact on child health, management, role of the mother and its prognosis and then to develop the study tools and the content of the educational intervention.

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## **2) Pilot study:**

A pilot study was carried out during September, 2009. It was conducted upon six mothers and their children with cancer to test the applicability of the study tools, setting and to determine the time needed to fill the sheet. Accordingly the necessary modifications were done in the form of adding questions as sources of mother information or omission questions as income of the family based on the result of the pilot study in order to strength their contents or for more simplicity and clarity. The pilot sample was excluded from the main study sample.

## **3) Field work:**

The field work started at November, 2009 to April, 2010, and follow up was carried out after three months at July, 2010. The purpose of the study was explained by the researcher to all mothers of children with cancer who were included in the study. The average time needed for the completion of each interview with mothers was around (30-45minutes).

## **4) Program Construction:**

The program was constructed based on the actual results that obtained from pre-program assessment using the interviewing questionnaire, practice checklist as well as literature review.

## **Program implementation:**

Implementation of the program was carried out at the previously mentioned settings. The subject material used has been sequenced through the 5 sessions; the duration of each session was ranged from 30 to 45 minutes including periods of discussion according to mothers' achievement, progress and feedback. Sessions started according to

mothers' suitable time, usually at 9 Am. Program was implemented through a period of 6 months, then follow up after three months, methods of teaching were used for knowledge lectures, group discussion, for practice demonstration, and re-demonstration. An instructional media was used including booklets, and colored posters.

### **Evaluation phase:**

Effect of the program on mothers was evaluated by comparing the pre and post assessment of the mothers regarding their knowledge, practice, pre assessment for quality of life for their children. The evaluation was done twice, immediately after finishing the implementation phase and three months later.

## **II. Administrative design**

Formal letter were issued from the Faculty of Nursing at Benha University to medical and nursing directors of the study settings. The title and objectives of the study was illustrated for whom to the managers as well as the main data items to be covered.

## **III. Statistical design**

The collected data were organized, categorized and analyzed using SPSS Version 11.0 statistical software packages. Data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variables, and mean and standard deviations for quantitative variables. Paired t- test, Chi-square test, Correlation coefficient at P-value =  $\leq 0.05$  was considered significance.

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**\*The findings of this study can be summarized as follows:**

- The mean age of children was  $5.6 \pm 1.95$  years, less than three quarters 71.7% were males, the half (50%) of them were in nursery school, and more than one third (48.3%) of them had leukemia.

- The mean age of the studied mothers were  $32.9 \pm 6.9$  years. While more than half (56%) of the mothers had higher education and the majority (91.7%) were house wives.

- The study reflected that the majority (96.7%) of studied mothers had family size ranged from 3-6 members, and more than half of children (60%) reported no family history of cancer, meanwhile (40 %) reported had family history of cancer and half (50%) of children's relatives were from the third degree of kinship.

- The study showed that more than two third (73.3) of mothers reported the common age of childhood cancer at all ages, meanwhile more than one thirds (33.3%) of them acquired their information from child's doctor. Meanwhile (23.3%) of them obtained their information from nurses.

- As regard method of childhood cancer treatment the study reflected that, more than half (58.3%) of mothers reported chemotherapy. Furthermore regarding alternative therapy (68.4%) of mothers uses alternative therapy.

- The study showed that total mother's knowledge about childhood cancer and chemotherapy pre program were 3% satisfactory knowledge compared to mother's knowledge immediate post and after three months were 90.1% and 88.8% respectively.

- In relation to total mother's practice related care of their children with cancer pre program mothers practice were 2% compared to immediate post and after three months were 81.1%, 78.8%.
- The study illustrated that there were statistically significant difference in sensation and mobility ( $P < 0.05$ ), while there were highly statistical significant difference in other attributes of QOL and performance status of children ( $p < 0.001$ ).
- The study pointed out that significant positive correlation of total mothers' knowledge and total practice with age and educational level, while regarding total QOL there were significant positive correlation were found with educational level. Finally regarding performance status of children there were significant positive correlation with family size and duration of disease.
- The present study revealed that there were statistically significant positive correlation between total mother's knowledge score and their total practice score at pre/ immediate post and after three months of program implementation ( $p < 0.01$ ).
- There were highly statistically significant positive correlation between total mothers knowledge scores, and QOL at pre/and after three months during program implementation ( $p < 0.01$ ). There were also, a statistically significant positive correlation between total practice scores and QOL at pre/and after three months during program implementation ( $p < 0.05$ ).



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**\*Conclusion:**

In the light of the study findings, it was concluded that mothers' knowledge and practice related to care provided to their children with childhood cancer was pre-program deficient knowledge and practice. This lead to a negative impact on their ability to care and QOL of their children. Several socio-demographic factors had their reasonable impact on mothers' knowledge and practice, such as level of education and family size. The developed educational intervention program was lead to significant improvements in mothers' knowledge, practice and QOL of their children after three months. This means that the research hypothesis of the educational intervention for mothers about care of children with cancer would enhance their QOL and the presence of positive correlation between their knowledge and practice was achieved throughout the study.

**\*Recommendations:**

Based on the findings of the current study, the following recommendations are proposed;

- ✎ Provide mothers of children with childhood cancer by updated posters and Arabic booklets about childhood cancer which contain an action plan suitable for each child's cancer nature in order to facilitate improving their knowledge as they considered the main member in children's care team.
- ✎ The findings highlight the importance of repeated evaluation of HRQOL in children undergoing cancer treatment and consideration of specific differences between diagnostic groups.